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# Insulin price spike leaves diabetes patients in crisis

**Andrew Schneider Special to the Gazette**

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Insulin, in various forms, has become so expensive that some diabetes patients are forced to choose between the lifesaving drug and other essentials like rent and food.

Andrew Schneider

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A massive spike in insulin prices is causing a health crisis for millions of diabetes patients who depend on the lifesaving drug, doctors say.

**EXHIBIT 2**

Now, after years of rapid increases having nothing to do with available supply and not matched elsewhere in the world, those in the U.S. insulin supply chain are blaming each other.

Tens of thousands of medical professionals are engaged in an intricate therapeutic ballet performed to protect the health, limbs and lives of the almost 30 million people in the U.S. suffering from diabetes.

But their efforts have been dramatically complicated by the soaring increase in the cost of insulin. They find themselves balancing the cost of the essential medication and their patients' ability to pay.

"The manipulation of insulin cost is a medical crisis in Montana and everywhere else in this country," said Dr. Justen Rudolph, a diabetes specialist at St. Vincent Healthcare in Billings. "My patients having trouble with their insulin availability range from teenagers to a 90-year-old man, and there's not a day that goes by when I'm not talking to a patient about the cost of their insulin.


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"They try to spread out the insulin they have to make do, and that's not how you can control diabetes," said Rudolph. This hit-or-miss medicating concerns many practitioners.

“Precision is needed to ensure the patient is getting the best type of insulin for their specific condition, in the right doses, at the right time to achieve the greatest benefit,” said Dr. Irl Hirsch, professor of medicine in the Division of Metabolism, Endocrinology and Nutrition at the University of Washington in Seattle.

State statistics and those of the American Diabetes Association show that 65,000 to 70,000 people have been diagnosed with diabetes in Montana, and another approximately 26,000 are believed to have the disease but have not been officially diagnosed.

In Missoula, Certified Diabetes Educator Carla Cox of the Providence Medical Group cautioned that switching to other forms of insulin “can present a greater risk because it is less like the action of insulin produced by the pancreas.”

**Prices soaring**

From 2011 to 2013 the wholesale price of insulin went up by as much as 62 percent. From 2013 to 2015 the price jumped again, from a low of 33 percent to as much as 107 percent, said Dr. Mayer Davidson, professor of medicine at the Charles R. Drew University of Medicine and Science in Los Angeles, who has carefully tracked the rapid and repeated increases.

“This borders on the unbelievable,” Davidson said, citing an extremely concentrated insulin which “in 2001 had the wholesale price of $45. By last year, the cost had skyrocketed to $1,447” for the same monthly supply.

Susan Pierce, a diabetes educator at Philadelphia’s Chestnut Hill Hospital, said she’s seeing similar increases, with her patients reporting that the cost of their insulin is doubling, tripling or worse.

“People who paid $200 or less are now getting bills of $400, $500 and even more for the same amount of insulin. Meanwhile, most insurance is paying less for medications and the required co-pays are higher, so it is a double whammy that prevents the patient from getting the insulin to stay alive,” said Pierce.

The medical community is concerned about patients who can't afford their insulin, "so what they have to do is they ration it," said Davidson, who has been heralded for his creation of programs to get quality diabetes treatment to underserved communities.

"They take it only three or four times a week instead of every day, in order to make it stretch, and that's dangerous," he said.

Diabetes specialists attack their patient's increase or decrease of blood sugars with the finesse of a commander plotting how to use limited troops and supplies in a continuing battle.

Patients and their practitioners live in a world where they must select and prescribe insulin which either institutes immediate changes in glucose or blood-sugar levels, or is long-lasting and doles out the vital medication over hours.

"We are not talking about concierge medicine, or just fine-tuning insulin therapy or something that a patent can live without. We're talking about survival. Don't let anyone sugarcoat it," warns Hirsch.

**"As much as her mortgage"**

The effects of diabetes are enormous. The disease is a leading cause of blindness, strokes, kidney failure, heart attacks, nerve pain and amputation of the feet and legs.

Hirsch and many of his colleagues are not subtle when they describe what "price gouging of a medication required for survival" is doing to their patients.

"I had a patient tell me her insulin bill is suddenly costing her as much as her mortgage," Hirsch said.

Others tell similar stories.

Dr. Claresa Levetan, chief of endocrinology at Chestnut Hill Hospital, said "just about 100 percent of them are having problems affording the higher cost of insulin."

“I see people every day in the hospital because they can’t get their required doses of insulin. Many are in the ICU with what is called diabetic ketoacidosis, a life-threatening condition. This lack of insulin brings the patients to a critical juncture, where they will become extraordinarily sick, go into a coma and could ultimately die.

“I have patients who tell me that they have to make a decision between food and insulin, and their rent and insulin.

“I mean, seriously, food, rent or insulin,” she said.

**Where prices get hiked**

Pricing of insulin, as with other medications, is controlled by the manufacturers, the insurance companies and pharmacy benefit managers – the middlemen who negotiate the prices that the insurance companies pay.

“Both the pharma company and the pharmacy benefit managers jack up the cost,” said Hirsch, a former editor-in-chief of the journal Clinical Diabetes, published by the American Diabetes Association.

“We don’t know what the benefit manager is paying for the insulin from the pharma company. It’s backroom deals,” Hirsch said. “You can call them rebates, you can call them kickbacks, you can call them bribes, but those are secret deals on which we don’t have the details.”

Pharmacy trade associations are pushing congressional committees and state regulators to investigate the pricing practices of these powerful benefit administrators. Of significant concern is a “clawback fee” that the benefit controllers demand the pharmacies impose on patients on top of their copays.

Most professionals on the front lines blame the snowballing costs on the almost complete lack of regulation of pharmacy benefit managers.

“But the companies say no, no, no. It’s not us,” said educator Pierce.

"You may not be able to prove who's behind the price rigging, but remember these prices are not an issue in Canada or in Europe or other countries where the governments keep the drug makers from going wild. It's only in America."

Nevertheless, some diabetes experts say the pharmacy industry should not be tarred with the same critical brush.

"Think of all the good things they actually do," said Cox in Missoula, and ticked off programs for many low-income, uninsured people, as well as the industry's support of children at diabetes camps and professional conferences.

**Drug makers blamed**

Three major pharmacy benefit companies were asked to comment on the insulin price increase. Only one, Express Scripts, the largest benefit manager in the U.S., replied.

The cost of insulin is high for patients because "drug makers continue to increase prices significantly each year, and there is no generic insulin available on the market," said Jennifer Leone Luddy, Express Scripts spokesperson, who added that her company's mission is "to keep prescription medication affordable and accessible."

She described a major effort "to ensure patients get the right medication, are using and achieve the best results from their medication."

The company seeks the most cost-effective medications, she said, but added that Express Scripts does not establish the price a patient pays for any medication, and its clients – employers, health plans and government agencies – decide how much will be paid by a patient.

In Gainesville, Texas, Jerry Meece, a clinical pharmacist and certified diabetes educator, said he spends far too much time trying to figure out what patients can afford versus what meds are most appropriate for them.

“These patients are desperate. They do without their insulin, skip doses, lower their prescribed dose to stretch out the insulin they have, and end up in the emergency room or ICU with long-term complications such as kidney failure, leg amputations or vision problems,” Meece said.

Even some patients who can afford the higher prices are endangered because the benefit managers are playing musical chairs with the different brands of insulin they authorize, some doctors said.

“I’m being told to make patients switch their insulin for no good reason except to make somebody more money,” said Dr. Loren Wissner Greene of New York University’s Langone Medical Center.

Greene, an NYU clinical professor of medicine, worries that her patients are confused by the flip-flopping.

“I just barely taught them that the orange pen is the fast-acting insulin and is to be taken with meals and the gray one is the slow-acting insulin to take at night. Now, suddenly, I have to switch them to a different brand to keep the pharmacy game-players happy,” she said.

“Big business wins again and the patients lose.”

Three pharmaceutical companies control almost all the world’s supply of insulin.

In addition to Eli Lilly, headquartered in Indianapolis, there is the Danish company Novo Nordisk, which says it makes half the insulin used by diabetics around the world, and the French company Sanofi, which says it has 18 percent of the market.

All three companies were asked why people buying their insulin were suddenly paying significantly more. Novo Nordisk and Sanofi did not respond to the question.

Lilly said it could not speculate on why individual costs went up.

“Lilly does not set the final price a patient pays for our medicines. Wholesalers and pharmacies ultimately price the product at retail,” said communication manager Julie Herrick Williams.

“The patient’s insurer, the type of plan and the individual pharmacy all play a role in the price,” she said. “Changes to the U.S. healthcare system are the primary driver for increased insulin cost for consumers. With the adoption of cost-sharing plans, like high-deductible health plans, more direct costs are shifting to the people who need treatments.”

Insulin production earns pharmaceutical companies tens of billions of dollars. The three pharmaceutical giants made an estimated $12 billion to $14 billion in profits from the sale of insulin last year, according to preliminary figures gathered by industry watchdogs.

Insulin first hit the market in 1920 when three Canadian scientists donated the patent for their life-saving discovery to the University of Toronto for either one Canadian dollar or free – accounts differ.

Almost immediately, the university gave pharmaceutical companies, including Eli Lilly, license to produce insulin without payment to the school or the scientists, who won the Nobel Prize for Medicine for its creation. The magical concoction – extracted from the pancreases of pigs and cows – was distributed almost worldwide within months. Since there was no pharmaceutical treatment at the time, only rigid and unhealthy diets, countless lives were saved.

Eli Lilly’s corporate history reports that it took more than 4,000 pounds of animal pancreases to produce a cup – 8 ounces – of insulin. Each year the company used organs from 60 million animals to produce enough insulin for U.S. diabetics.

Lilly looked for a better way to produce the vital medication, and in 1978, in a landmark in genetic engineering, Genentech came up with the answer. Genentech’s scientists cloned a synthetic insulin from a human insulin gene and a benign strain of

the food-poisoning bacteria E. coli. It was the first laboratory synthesizing of DNA that resulted in a much-needed medication, and animal-based insulin was on its way out.

Physicians are insisting that a less-expensive alternative has to be found, and questioning why a medicine nearing its 100th birthday is still so expensive.

Hirsch and his colleagues are lobbying hard to end the price gouging.

“The government is going to have to get involved and it’s going to get ugly,” said Hirsch, who has lived with the disease since his youth. He was diagnosed with diabetes when he was 6, and his younger brother was told he had the disease when he was 15.

“The well-being of our diabetes patients must come before the profit-driven games being played over the price of the clear liquid that keeps them alive,” he said.

Andrew Schneider, an award-winning public health journalist, is based in Missoula.

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